



Healthy Parent Carers – Summary of Results from our Feasibility Study

What is the programme?

Researchers at the University of Exeter and parent carers co-developed the Healthy Parent Carers programme to improve the health and wellbeing of parent carers of children and young people of all ages with special educational needs or disabilities.

The programme is led by parent carer lead and assistant facilitators and involves working with others in a group to make small changes in their daily lives to improve their health and wellbeing.

The programme emphasises the importance of parent carers taking time to look after themselves and focuses on doing activities we refer to as CLANGERS: Connect, Learn, be Active, Notice, Give, Eat well, Relax and Sleep. There are online resources available to go along with each session.

The Healthy Parent Carers programme was inspired by and developed together with input from over 40 parent carers from the [PenCRU Family Faculty](#) since 2014. These parent carers worked together at each stage to ensure that the programme and the research project were being run in ways that were likely to be suitable, acceptable, relevant, and meeting the needs of parent carers.

The research team also met regularly with professionals including representatives from the local authority in Devon, public health, parent carer forums in the South West, relevant charities, and special schools.

What we did in the feasibility study

We wanted to see whether the programme can be delivered in the community by newly trained parent carer facilitators and whether participants would engage, stay involved and perceive benefits.

We also wanted to find out whether we can test the programme in a trial to see whether it improves health and wellbeing and is good value for money. The most unbiased test is a randomised controlled trial. This study tested whether this kind of trial would be feasible to run in the future.

Nearly 200 people expressed interest in participating. Of these we assigned 92 parent carers in a random way to either receive the facilitated group intervention (47 parent carers) or to receive only the Healthy Parent Carer online information (45 parent carers).

Everyone was asked to complete online questionnaires measuring aspects of their health and wellbeing before and after the programme and again 6 months later.

We interviewed 22 of the parent carers who took part – 12 who took part in the group programme, 4 who could not attend any group sessions, and 6 who only received access to the online resources. We also held a focus group with all facilitators.

We used the feedback that we collected to refine the programme training, delivery, and content.

What we have learned

What went well

An important part of this project was collecting feedback from parent carers and facilitators and finding out what we can do to improve the programme for the future.

Overall, the programme was well-received and most parent carers said that it helped them to improve their health and wellbeing.

Feedback from both facilitators and participants was mostly positive:

“It was really good. I came in not expecting much, to be honest. Not knowing what it would entail. I learnt a lot.”

“It’s brilliant, for so many different reasons, not just awareness, but the coming together of people.”

“Meeting people who understand and ‘get it’ reduced my isolation. Having parent carers as facilitators helped a lot.”

“It was fantastic. I think it was really well done. (...) I think it’s changed my life.”

Most (85%) of those that participated in the groups liked this format, although many appreciated the flexibility of the online resources. 67% of parent carers in the group programme reported that it helped them to improve their health and wellbeing, with 76% reporting making changes.

Parent carers who were interviewed liked the opportunity to share with other parent carers in a supportive setting. They also noted that having parent carer facilitators was important for this.

Lastly, we learned that having online resources is valuable for parent carers who may be unable to get out of the house to take part in groups due to their caring role.

What we could improve

Although parent carers had positive experiences in smaller groups, most said that slightly larger groups would be good for providing a variety of perspectives. The facilitators also preferred larger groups as some activities were difficult to facilitate in smaller groups.

Nine participants did not find the programme useful and five felt neither positive nor negative. Eleven (24%) parent carers in the group programme reported not making any changes due to social care needs, access to respite, work situation, or it being a difficult time. A few parent carers struggled with some of the activities. Some also reported not feeling a connection with others in their group in the early sessions. However, at the end of the programme all participants said they felt included and part of their groups.

Several parent carers were unable to attend any sessions, often because their circumstances changed after signing up. We learned that we should plan larger groups so that each group will still have enough parent carers to enable the activities and discussions to run well. More importantly, we are exploring other ways to enable parent carers to attend, including running online groups.

Some of those who were not in the group programme missed the ability to share ideas and problem-solve with peers. Online group delivery using platforms such as Zoom may provide a way to improve access for some parent carers.



How we are refining the programme

The feedback that we received from participants and facilitators has helped us to improve the programme in many ways. We looked at all of the suggested changes or areas for improvement and discussed these among the research team and with our parent carer collaborators to find the best ways to address them.

These discussions yielded a detailed list of improvements that we could make to the implementation, training, delivery, and content of the programme. We have written new manuals that can be used in future training and delivery. Some of the examples of changes that we have made are:

- Parent carers will be provided with a photo of their facilitators and an opportunity to let their facilitators know about any support they may need ahead of time.
- Examples of goals are now provided in the resources.
- We have created and selected new videos that are more relevant to parent carers.
- We have written key 'take away' messages for each video.
- We provide more practice for facilitators in training and clarified the roles of the facilitators.
- We have changed the minimum group size from 4 to 6.
- Due to the pandemic we modified the programme to be delivered online via Zoom and have recently piloted this new format with two groups this year.
- We are preparing to train more facilitators and run further groups in the coming year with potential long-term delivery partners Contact, Council for Disabled Children and Local Authorities and other charities.

We are enormously grateful for the candid feedback that everyone provided to help us to refine the Healthy Parent Carers programme so that we can continue to improve what we do.

Academic papers

More details about this study can be found in our two published academic papers (free access):

Feasibility results paper: <https://rdcu.be/cpN8y>

Feedback and programme refinement paper: <https://bmjopen.bmj.com/content/11/8/e045570.full>

Videos

We worked with some parent carers to create a series of short films about their experiences:

- Healthy Parent Carers (3:54 minutes): <https://vimeo.com/376771910>
- Why is Healthy Parent Carers needed (1:02 minutes): <https://vimeo.com/433957740>
- Taking part in the programme (1:05 minutes): <https://vimeo.com/433964299>
- Impact of Healthy Parent Carers (51 seconds): <https://vimeo.com/436464943>

We also asked two facilitators who delivered the programme to share their thoughts:

<https://vimeo.com/432838782>

For more information, please feel free to contact the PenCRU team any time at:

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